

# The multifaceted role of the Epilepsy Specialist Nurse: Literature review and survey study on patient and medical Staff Perceptions

Il ruolo multidimensionale dell'infermiere specialista d'epilessia: revisione della letteratura e indagine sulle percezioni di pazienti e medici

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## RIASSUNTO

**BACKGROUND.** Epilepsy is frequently accompanied by learning, behavioural and psychological difficulties, therefore the management of this pathology extends far beyond the use of anti-epileptic drugs. The specialist-nurse-service provides a multifaceted management. This study adds new points of view on how epilepsy-specialist-nurses work, the benefits they produce and their feedback.

**OBJECTIVES.** The study was conducted to analyse the role of the epilepsy-specialist-nurse, its competencies, its impact on patients and healthcare system and its relevance in patient and medical-staff perceptions, to give new suggestions on how it can be useful in epilepsy teams.

**METHODS.** Literature review to analyse epilepsy-specialist-nurse role; a quantitative research with descriptive approach to examine patients' (11) perceptions using a novel-questionnaire; applied qualitative analysis of medical staff (4) perceptions through semi-structured interviews.

**RESULTS.** The epilepsy-specialist-nurse has the competences to manage the epilepsy-related issues that extend beyond medications. Patients value the ability of specialist-nurses to answer their multifaceted needs, to dedicate them enough time to discuss the impact of epilepsy on everyday-life and their feelings, giving suggestions. Doctors collaborating with specialist-nurses recognize their valuable contribute. Doctors give more information on epilepsy and medication-issues: patients prefer to consult a doctor for these issues.

**CONCLUSIONS.** The holistic way adopted by specialist-nurses in addressing patients' needs is fundamental to improve patients' health and well-being. Medical and nursing ability to address epilepsy-related issues in a very similar way - in the items analysed - may reveal that specialist-nurses can provide high-quality assistance while achieving cost-savings. It is needed to develop a structured pathway that allows the progression of specialist-nursing, to define a clear job description, and to obtain government recognition.

**KEYWORDS:** epilepsy; healthcare service\* development; nurse specialist; patient\* perception\*.

## ABSTRACT

**BACKGROUND.** L'epilessia è frequentemente associata a disturbi d'apprendimento, di comportamento e difficoltà psicologiche, pertanto, la sua gestione si estende oltre l'utilizzo di medicinali anticomiziali. I servizi infermieristici specialistici forniscono una gestione multidimensionale dell'epilessia. Questo studio offre nuovi punti di vista sull'attività infermieristica specialistica in epilettologia, sui suoi benefici e feedback.

**OBIETTIVI.** Lo studio è stato condotto per analizzare il ruolo dell'infermiere specialista d'epilessia, le sue competenze, il suo impatto sull'assistenza e sul sistema sanitario, le percezioni che pazienti e medici hanno su di esso, al fine di offrire nuovi suggerimenti sull'utilità di questo ruolo nei team d'epilessia.

**METODI.** Revisione della letteratura per analizzare il ruolo dell'infermiere-specialista d'epilessia; indagine quantitativa con approccio descrittivo per analizzare le percezioni dei pazienti (11) tramite neo-questionario; studio delle percezioni di medici epilettologi (4) attraverso ricerca qualitativa applicata, con interviste semi-strutturate.

**RISULTATI.** L'infermiere-specialista d'epilessia possiede le competenze per gestire aspetti correlati all'epilessia al di là della terapia farmacologica. I pazienti apprezzano l'abilità dell'infermiere-specialista a rispondere ai loro bisogni, a dedicare loro sufficiente tempo per discutere l'impatto dell'epilessia nella quotidianità, considerando le loro emozioni, e offrendo suggerimenti. I medici che collaborano con infermieri-specialisti riconoscono il loro prezioso contributo. I medici forniscono maggiori informazioni sulla patologia e sulla terapia farmacologica: i pazienti preferiscono consultare un medico per queste tematiche.

**CONCLUSIONI.** Le modalità olistiche con cui gli infermieri-specialisti considerano e gestiscono i bisogni dei pazienti sono fondamentali per migliorare la loro salute e benessere. Le abilità mediche ed infermieristiche nell'affrontare le problematiche relative all'epilessia in modo simile - per gli item analizzati - possono rivelare la capacità degli infermieri-specialisti a fornire assistenza di alta qualità, ottenendo risparmi economici. È necessario sviluppare un percorso strutturato che permetta l'evoluzione della pratica infermieristica-specialistica, definire una chiara job-description, ottenere il riconoscimento governativo/legislativo.

**PAROLE CHIAVE:** epilessia; sviluppo servizi sanitari; infermiere specialista; percezioni pazienti.

## INTRODUCTION

Epilepsy is a chronic, often long-term condition that can affect anyone from birth onwards. The causes of this pathology can be different: genetic, congenital, traumas. The diagnosis can be difficult, considering that also psychogenic non-epilepsy forms exist (Goodwin M. et. al., 2004).

Treatment is primarily through medication, but other therapies should be considered as soon as possible if the medicines do not produce the desired effects. The main secondary treatments could be represented by the Vagus Nerve Stimulator (VNS), the Ketogenic Diet (KGD), or the Surgery (Higgins A. et. al., 2017).

Seizures, although confusing and distressing for most patients, their families/carers, are only a part of the condition, and there are far wider issues that should be considered. Epilepsy is frequently accompanied by learning, behavioural and psychological difficulties, therefore, the management of this pathology extends far beyond the use of antiepileptic drugs and must address these additional problems (Appleton L.E., 1995). Increasing anxiety in the patient can produce overprotection from family/carers and a loss of identity, independence and self-confidence (S. Higgins, 2008). For this reason, it is important to help patients and their families to integrate as much as possible into educational, family and community life, maximizing their quality of life. The establishment of a nurse specialist service provides a more satisfactory and comprehensive management of these patients. Good clinical care in epilepsy should be based upon a multidisciplinary specialist service to which every patient (and family) should have access. A specialist doctor and clinical nurse specialist should be the key members of this service, in collaboration with other specialized professionals as neuropsychologist, psychiatrist, social workers, and occupational therapist (NICE, 2012). The Epilepsy Specialist Nurse (ESN) role is complex, diverse and multifaceted, operating in various settings. The main aim of the role is to provide high-quality effective assessment and care for patients and for everyone involved into the patient's welfare, to work collaboratively with other multi-disciplinary services, and to continually develop services that best suit the health care needs of epileptic patients and their families (S. Higgins, 2008; Foley J., 2000).

Prevalence of epilepsy in the world is 0.5-0.8 %, in Italy is about 0.6% (ca. 350.000 persons). It is evenly distributed in countries with the same socio-economic level, and higher in those under-developed. Incidence varies from 40 to 70 every 100.000 persons/year in industrialised countries (in Italy ca. 30.000 cases/year) and from 100 to 190 every 100.000 persons/year in those under-developed. Mortality rate for epilepsy patients is 2/3 times higher than that of the general population. It can be due to epilepsy itself or to an incorrect management during the seizure. (FOREP, 2012).

In Italy epilepsy is mainly treated with medical/surgical

therapy. Epilepsy nursing programmes do not exist yet and therefore epilepsy nursing services are not established in clinical practice. Some organisations (ESN Italia/GINP, Federazione Italiana epilessia, Lega italiana contro l'epilessia) recognise the importance of ESN role, however a deeper knowledge on this role is necessary, so that educational programmes are established and then activated.

The study was conducted to analyse through the literature review the role and the competencies of the ESN, to give an overview of the role, and then investigate the perceptions that epileptic patients and medical staff collaborating with this specialist role have on it. Since the survey will be conducted in a highly specialised epilepsy centre in Denmark (Filadelfia Hospital), the aim of the study is to give new suggestions on how this role can be useful in every epilepsy teams – consistently with the findings in that setting.

## METHOD

### Literature Review

This study has a mixed-method structure. First, a literature review was conducted to analyse the characteristics and the competencies of the ESN to give an overview of the role. The following databases were consulted in May 2017: Chinal, PubMed, Trip-Database.

No temporal limits were applied.

Key words used (linked with the boolean operator AND): epilepsy, healthcare service development, nurse specialist, patient perception.

Inclusion criteria:

- Any study (English and Italian language)

Exclusion criteria:

- Abstracts

### Documents about CSN role in non-epilepsy settings

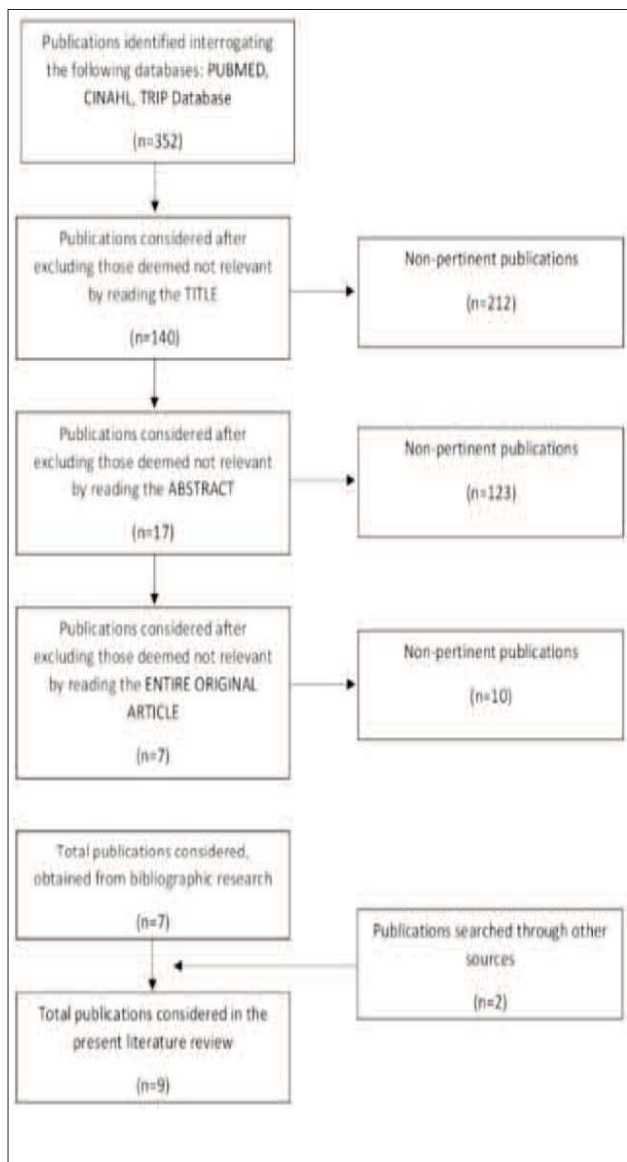
Afterwards, a survey was conducted to analyse epileptic patients' perceptions on the ESN role, through an observational descriptive study using a novel questionnaire; then a qualitative research was performed, about medical staff's perceptions on the ESN role through semi-structured interviews.

### Patients' Perceptions' Analysis

A 12-questions questionnaire was created by the author to conduct a quantitative research with descriptive approach, analysing patients' perceptions on the ESN role. This novel questionnaire is not validated but it has been checked and approved by the research nursing team of Filadelfia.

To design the novel questionnaire, examples of validated questionnaires focusing on patients' perception in health-settings were examined (Marshall G.N., Hays R.D., 1994; Hawthorne G. et al., 2014; Ruggeri M., Dall'Agnola R., 1993). Afterwards, the questionnaire was created using those questionnaires as models, on the basis

Figura 1. Flow chart of the research strategy



of the items collected from the literature and with the support of a PhD epilepsy-nurse, a website (Survio.com) and documents (Cecchetto P., 2011) for the creation of novel questionnaires.

The novel questionnaire examines, on an ordinal scale, some services that the patients with epilepsy and their families can receive: the importance of these services for them (1=not important, 2=moderately important, 3=important), if they are mostly provided by the specialist nurse or the doctor/other health professional, and in which extent (1=not at all, 2=a little, 3=fairly, 4=largely). The services analysed concern the provision of information about epilepsy, treatment, seizures and how to manage them, the possibility to discuss, counselling for any issues the provision of clinical records and information on how lifestyle can be adapted (see Appendix). Finally, the patients were asked to evaluate their personal inclination toward the specialist nurse or the doctor. The patients/carers included were the ones attending the

epilepsy specialist nurses' clinics at Filadelfia Hospital both in adult and paediatric department in June 2017. When adult or paediatric patients were not able to answer the questions, their carer did. The questionnaires were handed out by the specialist nurses, after their consultations, to a total of 11 patients/carers (4 from the Adult Department and 7 from the Paediatric Department). The aim of this survey is to give new suggestions on the ESN role when implemented into practice, underline which activities patients consider more important for them, and which should be addressed more.

### Doctors' Perceptions' Analysis

To analyse medical staff's perceptions, using an applied qualitative research methodology, four doctors were interviewed (June 2017) at Filadelfia Hospital, with semi-structured interviews. They were asked about their thoughts on the ESN role and their collaboration, if, in their opinion, ESNs are useful in the clinical and organisational epilepsy care path, and in which way. The doctors interviewed were daily collaborating with the specialist nurses from at least 5 years, they were selected by purposeful sample, and they were both from Paediatric (3) and Adult Department (1). The aim of these interviews is to give an idea of what other health-professionals strictly collaborating with ESNs (in this particular setting of collaboration, still rare to find in Europe) think of that role, to show if there is evidence of productive and successful collaboration.

### Ethics

The surveys, ethics and the data collection were approved by the leaders of both Adult and Paediatric Department of Filadelfia Epilepsy Hospital. According to hospital policies, it was ensured all the legal permissions were fulfilled. The participants were all informed about the anonymity of the questionnaire, with written instructions as well as introduced orally to the questionnaire. They freely chose to complete the questionnaire and they were not forced to participate in the study. This study did not have any consequences on the patients' course of treatment. The doctors as well, freely chose to be interviewed, and they were informed verbally and in written form on the aim of analysis.

## RESULTS

### Literature Review

"Epilepsy specialist nurses should be an integral part of the network of care of children, young people and adults with epilepsy. The key roles of the ESNs are to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the patients, families, carers (...) Epilepsy patients should have access to (...) counselling services, epilepsy specialist nurses, timely and

appropriate investigations and referral to tertiary services” (NICE, 2012).

“ESNs are an expert and essential part of a multi-disciplinary team providing clinical and psychosocial information and support for individuals with epilepsy” (Epilepsy Action, 2010). The ESN’s work is complex and includes clinical interventions, psychological, social and educational support to patients and families. ESNs also provide assistance in neglected areas, such as the transition from paediatric to adult care and pre-conception counselling for women. 70% of ESNs’ worktime is spent on patient-related activities, the other 30% is about teaching, administration, professional development, and research.

In particular, most of the ESNs are involved in joint medical clinics or hold nurse-led clinics, a minority work in multi-disciplinary clinics. ESNs make decisions within the clinical setting from 25 to 100% of the time. The ESNs involvement in drug management is assessed at level 4 out of 5 (“a lot”) (Goodwin et. al., 2004).

11 heart-competencies of ESNs practice can be identified (Higgins S., 2008). They plan patient-centred care; assist in diagnosis, investigation, treatment and management; provide counselling and liaising within other services; provide services to support people living independently at home; improve palliative care services; discuss the effects of seizures on the patient’s everyday life and inform family/carers on how their lifestyle can be adapted; and liaise with ward staff to improve inpatient care. Clinical Nurse Specialists (CNSs) are coordination points among multi-disciplinary teams in primary and secondary care - and other institutions as schools or workplaces- and act as source of specialist consultancy and education to other healthcare professionals. The ESN also acts as a contact person for patients through telephone helplines, that are cost and time saving, both for nurses, consultants and patients, and seem to be an appropriate way to provide low cost care while reducing the burden on patients to travel to the hospital (for example). Some ESNs work autonomously, running independent nurse-led clinics and managing those who are long term seizure-free to discuss the risks and implications of withdrawing treatment. The deriving savings are mainly attributed to: medication management, patients, carers and family education (greater self-management) on the use of rescue medications, telephone consultations, reduction of Accident and Emergency admissions for chronic epilepsy. This can further reduce consultants and General Practitioners demand (and burden - allowing them to concentrate on more complex cases), lower admissions and waiting list time, producing consequent cost-savings. Furthermore, patients value meeting the same person, developing a relationship with the ESN, spending less time awaiting appointments and having longer consultation with the ESN they often feel more comfortable with. Many ESNs also care for patients with non-epileptic seizures, providing appropriate management plans. ESNs participate in continuing research and audit to improve the quality of specialist care provided,

reviewing services by developing standards, policies and guidelines (Epilepsy Action, 2010; Goodwin et. al., 2004; Appleton R.E. and Sweeney A., 1995). The ESN’s proactive, patient-centred and holistic approach may be considered successful to solve most of the social, educational and psychological problems in an outpatient setting, and may obviate the need for formal psychological intervention, or for further medical consultations. Parents are frequently reluctant to open up and discuss their concerns with medical staff because they think either that the doctors are too busy or their questions and anxieties are too trivial – Specialist Nurses are seen as more approachable (Appleton R.E. and Sweeney A., 1995).

When epilepsy patients are questioned about their perception of the service they receive from either a general-practice setting or hospital-based clinic, the results show that nurse-run clinics were well attended, and there was a significant improvement in the level of advice recorded. Patients identified a positive contribution of the ESN in empathic listening, communication of information, and in improving the continuity of care. (Foley J. et al., 2000).

Patients also suggested some differences about their clinical path before and after a CNS consultation (Appleton R.E. and Sweeney A., 1995). ESNs improve the understanding of epilepsy and its treatment, and therefore contribute to a better quality of life for people with epilepsy and their families. Patients in the 90% of cases were told and explained about their epilepsy-type by a CNS (instead of the 60% without a CNS), 100% of the time were explained by the CNS the side effects of the drugs used (instead of 40% without a CNS), and 90% of the time they were satisfied on the information received (instead of 44% without a CNS).

All the activities and competencies underlined can be gathered in four core values (Hopkins J. and Irvine F., 2012):

- Holist care: ESNs consider all the aspect of patients’ lives that epilepsy can affect, to provide a complete and effective care;
- Pro-active management: offering timely specialist interventions, anticipating problems;
- Continuity of care;
- Time for patients: ESNs can offer longer consultations than consultants or GPs and this makes patients more satisfied, reduces contact with other services and prevents emergency admissions. “It’s about the quality of care you give to the patients, not necessarily the numbers of people that you see”.

Four settings where ESNs are influential can also be listed (Higgins A. et. al., 2017):

- Clinical practice: across primary, secondary and tertiary care, including pregnant women, people with co-morbid physical and psychological health difficulties and people with intellectual disability. ESNs provide an in-depth comprehensive assessment that moves far beyond the only clinical aspects of the disease to incorporate lifestyle and psychosocial

issues, education, follow-up process, coordination of the care pathway and collaboration to the decision-making in the multidisciplinary team;

- Leadership: ESNs are involved in clinical and professional leadership, at both strategic and patient-level, to improve the quality of care for epileptic patients and influence policy and practice by developing guidelines, protocols, care pathways and educational programmes;
- Research: leading clinical audit, service evaluation, conducting clinical research, and spreading EBP among the multidisciplinary team members, patients, families and the general public;
- Patient/service outcomes: patients in ESN sites rated information and support received, involvement in care, co-ordination of care, and confidence in talking to and seeking advice from ESNs, higher than those in non-ESN sites. There are some evidences of decreased depression in the ESN group, and good evidence that patients' satisfaction and the process of care are improved with ESNs (Meads C. et. al., 2003). ESNs improve efficiency of the services, allowing doctors to utilise time more efficiently with cost saving implications. Patients who receive care in an ESN site have the same cost as those receiving non-ESN care, or sometimes even cheaper, due to lower primary and secondary care costs (674£ versus 858£). Therefore, ESN sites may be a good option to improve patients' experience, better management and coordination of care services at no change in costs. Despite all these results, a small proportion of epileptic patients prefer medical care as they are more trusting of their advice, especially about medications.

Many factors can influence the ESN role development, integration and sustainability. Favourable factors include the presence of national policies on the role, the support for the role among other health care personnel, the positive appraisals of ESNs by the stakeholders, and the presence of resources that allow the ESNs practice. Hinder factors include role overload, lack of ESNs within some services, limited access to some supports and resources, and the many requirements needed to become a CNS.

A factor that could act both as an enabler and a hinder is the acceptance of the ESN role by the patients and their families (Higgins A. et al., 2017). Factors affecting the ESN role can be collected into three main categories (Hopkins J. and Irvine F., 2012): clinical factors, policy factors and structural/organizational factors.

#### **Patient perceptions' Analysis on the ESN role at Fildelfia Epilepsy Hospital (DK)**

From the analysis of the questionnaires (11: 4-Adults, 7-Paediatrics) it emerged that most of the items are important, at maximum score, for patients - except items about dedicating time to talk with patients about their feelings, and informing patients on how their lifestyle may have to change, are sometimes scored as moderately

important.

ESNs scored better in 6 items out of 10, and doctors scored better in 4 items out of 10 (see Appendix).

Doctors give many information about epilepsy and seizures, and include the patients in the clinical path.

The patients feel that doctors debate to a greater extent than the nurses on issues concerning with medications they take (e.g. aim, side-effects, risks) and explain more clearly and exhaustively the different types of treatment.

On all the other items analysed, ESNs are preferred by patients.

They discuss with patients on how epilepsy can affect their everyday life, giving advice to help them to manage seizures and counselling for daily problems and specific issues.

Patients feel that ESNs dedicate more time than doctors to permit them to talk about their feelings and thought about their condition.

ESNs provide a bit more information on how patients' lifestyle may have to change or can be adapted, and providing clinical records.

Finally, it was assessed that most of the patients do not have inclination to address ESNs or doctors to ask for help and advice about medications, if they have any fears, worries or doubts coping with epilepsy, or if they need help for a better managing of their disease. They also expressed their feeling of being able to address to nurses and doctors in the same way, without uneasiness, when any help/support is needed.

#### **Doctor Perceptions' Analysis on the ESN role at Fildelfia Epilepsy Hospital (DK)**

From the doctors' interviews, it emerged that "ESNs are absolutely important and needed in an epilepsy service" for six main reasons.

- ESNs "act as a connection between patients and doctors": they facilitate and improve communication between families and health-staff, represent an additional point of contact for patients -because doctors are often too busy-, monitor treatments/treatments compliance, and clinical situation, helping in the following up and facilitating doctors in adjusting treatments;
- ESNs provide more advice and full information about epilepsy in general and specific aspects – "many times doctors do not have time for that". During their consultation ESNs discuss about some aspects that patients do not address with doctors, as implications of epilepsy in daily-life and everyday issues. ESNs dedicate more time to patients than doctors, they provide education to patients and families, but also to all medical and non-medical professionals involved in patient care, they make telephone consultations giving advice and information for every issue almost in every moment, "they say things in different ways than doctors do or

do not have time to, so patients can understand much more clearly”.

Some patients are more inclined to speak with the ESN, in that way the epilepsy team can have more information about their condition and, thus, manage the course of illness in a better way;

- The third reason why ESNs are important in doctors' opinion is that many ESNs also have sub-specialisations (VNS, Ketogenic Diet, Surgery) and in that way, “they can actively participate in the specialized care process”;
- ESNs also manage social and bureaucratic/administrative aspects, that doctors do not have time for. For instance, they dedicate time to contact co-workers, social helpers, special needs teachers, and other stakeholders to keep them updated or explain any support needed.
- They act an important role in the transition between paediatric and adult phase, e.g. talking about sexuality (and interactions between medications and contraception), alcohol or possible dangerous situations, such as getting driving licence without a stable pharmacological therapy.
- ESNs efficiently support doctors' workload, helping them to optimize their schedule, and work collaboratively to achieve better goals. “The ESNs have a crucial role in the care process and they make my life a lot easier”.

## DISCUSSION

The literature review confirms that ESNs should be an integral part of the network of care of children, young people and adults with epilepsy (NICE, 2012). However, there are many factors that can influence the ESN role development, integration and sustainability (Higgins A. et al., 2017; Hopkins J. and Irvine F., 2012). The ESN role is broad and multifaceted, providing effective healthcare through communication, information, advice and support. The ESN meets the complex needs of patients/families/carers through flexible high-quality patient-centred care. The ESN undertakes advanced activities such as independent prescribing, nurse-led clinics, triage, counselling, and provides educational, psychological and social support (Higgins S., 2008). Core values characterizing ESNs' role (Hopkins J. and Irvine F., 2012) are holist care, pro-active management, continuity of care and time for patients.

The Epilepsy Action (2010) attested that 70% of ESNs' worktime is spent on patient-related activities, the other 30% is about teaching, administration, professional development, and research. Essential activities of ESNs (Foley J. et. al., 2000) are: providing education, specialised clinics, clinical assessment, counselling; acting as a liaison among patients/carers and different health care professionals; dedicating time to risk and medications manage-

ment. ESNs also share many activities with consultants, allowing them to focus on more complex cases. These issues may solve most of the social, educational and psychological problems, and may obviate the need for formal psychological intervention and additional outpatient medical consultations requested (Appleton R.E. and Sweeney A., 1995). There are also evidences of cost-saving connected to ESNs' services, for instance, deriving from the ESN telephone consultations, the reduction of A&E admissions for chronic epilepsy where ESNs are active, and (Goodwin et al. 2004, Higgins A. et al. 2017) the substitution, performed by ESNs, of services usually provided by doctors, that decrease the cost both of clinic doctor time and reduction in GP visits. Patients who receive care in an ESN site have the same cost, or even lower, as those receiving non-ESN care, therefore, ESN sites may be a good option to improve epilepsy patients' experience, better management and coordination of epilepsy care services at no change in costs (Higgins A. et al., 2017). Among different settings, the activities of ESNs may vary. Most of them are involved in nurse-led clinics and join medical clinics, only a minority works in multi-disciplinary clinics. The level of involvement of ESNs in drug management may varies, but most of ESNs score at level 4 out of 5 (Goodwin et al., 2004). The CNS may improve the understanding of epilepsy and its treatment, therefore contributes to an improvement in the quality of life of patients and families, decreased depression and increased satisfaction (Meads C. et al., 2003; Appleton R.E. and Sweeney A., 1995). Summarizing, there are four settings where the ESN is influential (Higgins A. et. al., 2017): clinical practice, leadership, research and patient/service outcomes. Nevertheless, a small proportion of patients with epilepsy continue to prefer medical care as they are more trusting of their advice, especially about medications.

From the analysis of patient perceptions at Filadelfia Hospital, patients appeared to value all the services provided by the epilepsy team. ESNs are scored better than doctors at discussing how epilepsy can affect their everyday life, at giving advice and at counselling for daily problems and specific issues.

Patients feel that ESNs allow them more time to talk about their feelings. ESNs give more information on how patients' lifestyle may have to change, and providing clinical records. Doctors were scored slightly better than nurses at giving information about epilepsy and seizures, and including the patients in the clinical path. It also seemed that doctors debate to a greater extent on issues concerning with medications, and explain more clearly and extensively the different types of treatment.

The interviews to the doctors at Filadelfia Hospital testify that the medical staff recognizes the ESNs' importance and valuable contribute of both to the patient care-process and to the doctors' work: this could represent both a reason and a result of an efficient interprofessional collaboration.

## CONCLUSION

Despite many factors could hinder the development of specialist nursing, there are evidences that it is important to create a work environment that values the unique contribution that ESNs make to patient care, and support the development of their role. The holistic way that ESNs address patient needs, considering their clinical, social and emotional challenges, is fundamental to improve patients' health and well-being. There is a need to develop a more structured pathway that allows nurses to progress into specialist practice, as well as define a targeted job description, clearly describing specific skills and competencies of the ESN role. Furthermore, it is important that the government recognizes the role of specialist nurses as integral to the care of people with epilepsy, creating job position for this role. This might allow them to start working in new ways, more independently, including carrying out their own clinical-educational projects, ordering investigations, making and receiving direct referrals, managing patient caseloads, prescribing, running nurse-led clinics. Health authorities should make sure that every person with epilepsy receives personalized care, information and advice. This could be promoted by the development of multi-disciplinary epilepsy services, also through the implementation of ESNs. ESNs should always consider strategies to improve the information provided, and place emphasis also on other aspects as how to keep a seizure diary, how to explain epilepsy to others, and how to facilitate epilepsy management in everyday life/ school/ workplace. It is fundamental that the ESN service is understood by the population, in order to let everybody benefit from it, and not to be interpreted as a costs-saving exercise. It is also necessary that future specialist nurses are provided with adequate clinical and management education, mentorship, coaching and opportunities to advance their leadership competencies both at a national and international level. As specialist nurses, continual updating and service development are essential components to ensure expert and safe patient care.

“The multiple functions and benefits that ESNs can produce would be truly beneficial to patients and healthcare system when implemented in the context of a well-structured, well-resourced and fully coordinated epilepsy service” (Higgins A. et al., 2017; Foley J. et al., 2000).

When developing a business case for improving or implementing epilepsy services, there are some issues that should be considered (Joint Epilepsy Council, 2013). Most relevant issues that should be taken into account are the care-related, outcome-related, and service-related ones. It is needed to analyse how to approach and how to cope with them and possible consequent problems that should be solved. It is also important to define measures of success to compare with. Furthermore, the financial aspects should be analysed, together with the demographic aspects, the design and the evidences about the service which is going to be implemented.

As attested in the analysis conducted at Filadelfia Hospital on patients' perceptions, most of the times ESNs perform better than the doctors in the items considered, other times doctors perform better but only to a mild extent and in activities that are not typical of nursing. This means that ESNs could substitute doctors for the majority of these tasks they share, and this would lead to cost-savings – since nurses' salaries are cheaper than doctors' ones – and time-savings – since doctors could spend less time on tasks that ESN can perform in the same way or even better –. Another consideration is that, since patients receive more information and advice from ESNs, this may lead to: higher patients' satisfaction that would conduct to less additional consultations with doctors, nurses or other healthcare professionals, that would mean cost and time savings. More advice received may also lead to a higher awareness, better self-management, less complications and hospitalization, and, thus, cost savings and a better and more stable course of the disease. Naturally, all these outcomes can be reached only if the ESN service is well structured and well resourced. The study, consistently with the report of Higgins A. et al. (2017), also reveals that ESNs should improve some aspects of their work they less address, as education on epilepsy and seizures types, in order to improve the benefits they provide even more.

Other items where nurses perform worse than doctors – as advising on medications and treatment – are not typical nursing skills, and therefore there is a limited and unsure need to develop these abilities.

One of the main barrier to the development of the specialist nursing is the medical-class opposition, but the doctors' thoughts analysis reveals that when doctors and specialist nurses collaborate, the doctors become aware of the value of the ESNs, they are satisfied of their cooperation, and they do not oppose to their development, indeed they are grateful for the activities the specialist nurses conduct.

### Limits

One of the main issues of this study might be the highly specialised centre where it was conducted. It would be interesting to perform a similar analysis in a general hospital to compare the differences among the services provided and check if the results could be valid in other settings. A second limitation could be the small sample of patients and doctors, due to the difficulty to find patients able and willing to answer, and professionals conscious enough about the ESN role, which is nowadays still partially widespread. However, the doctors interviewed were well informed and might reflect the opinion of a small group but that could potentially grow in the future. Another limit could also be the limited measures adopted in the ordinal scale of the questionnaire to assess the importance and the provision of the services. For these reasons, the results might be considered only partially generalizable.

However, they can be useful to give new perspectives

deriving from the experience of a highly specialised context of multi-professionalism, that requires -and show the necessity and importance- of inter-collaboration, where every professional role needs to be as developed and integrated as possible.

#### What is already known about the topic:

Many factors act as a barrier to the development of the specialist nursing roles, but several evidences suggest that the ESN must be an integral part of the epilepsy-team, to address those issues that go beyond the medical treatment of the disease;

The main aim of the ESN is to provide high-quality assessment and care for epileptic patients and everyone involved into the patient's welfare, to work collaboratively in multi-disciplinary teams, and to develop services that best suit the health-care needs of epileptic patients and their families.

#### What this paper adds:

Specialist nurses are more inclined than doctors to some aspects of epileptic patients' care-path. Especially, ESNs better discuss how epilepsy can affect patients' everyday life, giving advice, and allowing them more time to talk about their feelings;

Doctors give more information about epilepsy and seizures, and include patients in the clinical path. Doctors debate more on medications-issues, also explaining the different types of treatment. For this reason, many patients still prefer to consult a doctor for issues concerning medications;

Medical staff collaborating with ESNs recognizes their valuable contribute both to the patient care-process and to the team's work; Specialist nurses could be a good chance to provide high-quality assistance, reducing doctors' workloads and achieving cost and time savings in an effective way.

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## Appendix

Subjective inclination to professionals		More to the specialist nurse	More to the doctor/ other health professional	In the same way
1.	To which professionals are you more inclined to ask for help/ advice/ suggestion? - About medications / treatment (doubts, risks, desire to change, ...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	- If you have fears about the disease / seizures, feelings, anxiety, worries, doubts, coping with epilepsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	- If you need help for a better managing of epilepsy in everyday life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Do you feel that you can freely count on the professional if you need any clinical-psychological support / general help concerning with your disease, without uneasiness or embarrassment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Services	Provided by											
	Importance			Specialist Nurse				Doctor/ other health professional				
	Not important	Moderately	important	Not at all	A little	Fairly	Largely	Not at all	A little	Fairly	Largely	
3. Give information about epilepsy, seizure types, and what happens during a seizure	1	2	3	1	2	3	4	1	2	3	4	
4. Discuss with you how having seizures can affect everyday life	1	2	3	1	2	3	4	1	2	3	4	
5. Provide you and your carers the necessary information to make you able to manage the seizures when they come	1	2	3	1	2	3	4	1	2	3	4	
6. Explain clear enough to you about the different existing options of treatment	1	2	3	1	2	3	4	1	2	3	4	
7. Discuss with you, dedicating enough time, about the medications you take (the aim, the side effects, the risks, ...)	1	2	3	1	2	3	4	1	2	3	4	
8. Take enough time to talk with you about your feelings and thoughts about your condition	1	2	3	1	2	3	4	1	2	3	4	
9. Counseling for any problems about how to manage your illness in everyday life or in specific situations (for instance, communication with institutions, schools, social workers)	1	2	3	1	2	3	4	1	2	3	4	
10. Inclusion in your course of illness and decisions	1	2	3	1	2	3	4	1	2	3	4	
11. Inform you how your lifestyle may have to change or can be adapted	1	2	3	1	2	3	4	1	2	3	4	
12. Providing you with clinical assessment documents or clinical records to have a report of your personal details, advice given, information on the care process	1	2	3	1	2	3	4	1	2	3	4	